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ABSTRACT

The second in a series of reports by a task force subcommittee on deinstitutionalization of developmentally disabled persons in Ohio, the monograph focuses on residential services. Basic planning principles, reflecting philosophical and legal concepts such as least restrictive alternative, normalization, and respect for human dignity, are reviewed. The next section considers the negative aspects of the continuum of residential services, including the following: (1) such a continuum is highly expensive to implement (most of the resources go to the more restrictive settings); (2) it reinforces and deepens the perception of difference in disabled persons; and (3) such a continuum prohibits development of a truly individualized program in congregated, segregated settings. In contrast to the continuum approach, the report cites advantages of the home-centered approach. Differences between a facility-based and home-centered approach are charted in terms of language, community presence and participation, program function, and decision making. Issues specific to children, adults, and handicapped persons with special needs (including the elderly) are noted. Aspects of management models needed to develop integrated residential options are described. Ohio's needs for preparing for transitions to a home centered residential system are briefly noted. Recommendations regarding general aspects, planning, training and technical assistance, funding, and monitoring and licensure conclude the report. (CL)

POSITION PAPER NO. 2

Residential Services in Ohio

The Need to Shift from a Facility-Based to a Home-Centered Service System

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Deinstitutionalization Task Force

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The Need to Shift from a Facility-Based to a Home-Centered Service System

Prepared by
The Community Services Subcommittee
Deinstitutionalization Task Force

Wade Hitzing, Task Force Member
Ronald E. Kozlowski, Project Coordinator
Elsie Helsel, Subcommittee Chairperson

The contents of this paper reflect official policy and positions of the Ohio Developmental Disabilities Planning Council.

December 1983

"ALL SUCH INSTITUTIONS ARE UNNATURAL AND UNDESIRABLE, AND VERY LIABLE TO ABUSE. WE SHOULD HAVE AS FEW OF THEM AS POSSIBLE, AND THOSE FEW SHOULD BE KEPT AS SMALL AS POSSIBLE. THE HUMAN FAMILY IS THE UNIT OF SOCIETY."

Samuel Gridley Howe

1866

This paper reflects the official position and policy of the Ohio Developmental Disabilities Planning Council. The development of this paper was supported by funds made available through a grant from the Ohio Department of Mental Retardation and Developmental Disabilities, authorized under P.L. 95-602 to further the attainment of the goals and objectives of the Ohio Developmental Disabilities Planning Council.

The contents of this paper do not necessarily reflect the position or policy of the Ohio Department of Mental Retardation and Developmental Disabilities, and no official endorsement of the above agency should be inferred.

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PREFACE

Changes in the philosophy of services and a growing concern for the rights of persons with developmental disabilities have led to a national deinstitutionalization movement. Thus, the service system for Ohio's citizens with developmental disabilities is in a period of transition as the state moves from an institution-based to a community-based service delivery model. Although the deinstitutionalization movement has increased the move toward community-based services, numerous constraints continue to challenge this effort. With the transition in progress, the development of long- and short-term service development plans is critical to the evolution of a cohesive system that uniformly provides appropriate and adequate services. Identification of the nature and shape of the desired service system, the recognition of existing and potential constraints, and the development of an effective planning process must occur to assure that quality services are available now and in the future.

It is within this context that the Ohio Developmental Disabilities Planning Council created the Deinstitutionalization Task Force Project. The purpose of the project was to establish and provide staff support to a Deinstitutionalization Task Force, which was formally constituted in March 1981. The Task Force, composed of representatives from various agencies and consumer groups (see inside back cover), was charged with the responsibility to identify major issues related to deinstitutionalization and to develop recommendations for increasing the availability of appropriate services to persons with developmental disabilities.

Given its charge, the Task Force had two major options in terms of where to focus its attention: (1) on the nature or structure of the service system or (2) on the service process. Because of the scope and complexity of the issues related to deinstitutionalization, the Task Force decided to focus on the nature or structure of the service system. This approach was chosen because (1) an appropriate structure is a necessary condition for the development of quality, appropriate services and (2) many process guidelines and safeguards are already present in rules and regulations. By focusing on the structure of the service system, the Task Force could then develop a plan containing: (1) a broad outline of the proposed service system and (2) a broad outline of proposed planning strategies.

The Task Force considered this option as most consistent with the Developmental Disabilities Planning Council's advocacy function, in that the development of a broad outline of the proposed service system facilitates systemic change. Long-range service goals define how things "ought to be" and can be used to guide short-term transition planning.

The Task Force initially sought to identify the various legal and philosophical principles in the field of developmental disabilities and to define with a high degree of clarity the actual issues surrounding deinstitutionalization. These deliberations were based on experiences in Ohio and augmented by the experiences of some of the more active state programs outside of Ohio. The basic concepts that emerged were used then to guide the planning process.

This led to the second step, which was to apply these concepts to a service system for persons with developmental disabilities. The Task Force selected the following broad areas in which to concentrate its efforts: (1) the role of institutional services (2) residential services (3) adult services (4) informal and formal supports, and (5) administrative structure and finance. To provide broad-based professional and consumer input in addressing these general topical areas, a subcommittee structure was established. The following subcommittees were constituted by the Task Force:

- o Institutional Services Subcommittee
- o Community Services Subcommittee
- o Prevention of Institutionalization Subcommittee
- o Finance Subcommittee

This structure essentially provided a two-tier review process. Each subcommittee was charged with the initial development of a position paper on a selected topic. The Community Services Subcommittee was charged with initial development of position papers on two topics. The papers were then all submitted to the Task Force for review and/or modification, and subsequently adopted as official position papers of the Task Force. The five position papers provide statements of program philosophies and service strategies that can be used to develop quality services for persons with developmental disabilities. Each position paper contains a series of broad recommendations that the Task Force believes should be used in developing specific implementation plans.

The Task Force believes that the position papers describe a realistic direction for Ohio's service system and should be used as roadmaps for developing quality services for persons with developmental disabilities.

Papers in the series include:

Position Paper No. 1:	THE FUTURE OF INSTITUTIONAL SERVICES IN OHIO: Do We Need to Plan for Institutional Services?
Position Paper No. 2:	RESIDENTIAL SERVICES IN OHIO: The Need to Shift from a Facility-Based to a Home-Centered Service System
Position Paper No. 3:	FUTURE DIRECTIONS IN ADULT SERVICES
Position Paper No. 4:	PROMOTING QUALITY COMMUNITY LIVING THROUGH FORMAL SUPPORT SERVICES AND INFORMAL SUPPORTS
Position Paper No. 5:	FUTURE DIRECTIONS IN ADMINISTRATIVE STRUCTURE AND FINANCE: PREREQUISITES FOR COMMUNITY-BASED SERVICE.

Nisonger Center
The Ohio State University

Ronald E. Kozlowski
Project Coordinator

ACKNOWLEDGMENTS

The Deinstitutionalization Task Force Project was originally established through a letter of agreement between the Ohio Developmental Disabilities Planning Council, The Department of Mental Retardation and Developmental Disabilities, and the Ohio State University Research Foundation (Nisonger Center) to identify issues and develop recommendations relative to deinstitutionalization in Ohio. The products of the Task Force are the result of a collaborative effort by various individuals, representing a variety of organizations and agencies, who participated on the Task Force or its subcommittees, or otherwise provided assistance in developing the various position papers. Forty-two individuals, representing thirty-three organizations and agencies, contributed to the development of the five papers. Appreciation is extended to those individuals, who graciously gave their time, patience, and expertise.

A special mention is made of the sincere efforts that were put forth by Dr. Jerry Adams, who conceived the project and devoted tremendous personal energies toward making project activities viable. Succeeding Dr. Adams, Dr. Denis Stoddard also devoted much personal energy in supporting the project. Dr. William Gilbert and Dr. Henry Leland (Co-chairpersons) guided the Task Force through its deliberations and saw to it that the Task Force completed its tasks. Appreciation is also expressed to the Ohio Developmental Disabilities Planning Council for recognizing the significance of this project and providing funding for its activities, and adopting the position papers produced by the Task Force as official policy and position statements of the Council.

RESIDENTIAL SERVICES

A residential services program should provide assistance to persons with developmental disabilities so that they may live in settings that allow maximum:

- o Independence and human dignity
- o Presence and participation in community life
- o Status as valued community members
- o Potential for growth and development

It should be noted that this can be achieved without neglecting the person's need for supervision and care, and can be accomplished in settings that are typical of normal home life.

BASIC PLANNING PRINCIPLES

A necessary first step in the development of a systematic approach to the delivery of residential services to persons with developmental disabilities is the delineation of principles upon which the service system must be built. These principles, which reflect basic philosophical and legal concepts in the field of developmental disabilities, should guide the planning, development, and implementation of residential services.

LEAST RESTRICTIVE ALTERNATIVE

Attaining the least restrictive alternative requires that the living situation be the most age and culturally appropriate for meeting the person's needs for supervision and training, without imposing unnecessary modifications or denial of personal rights. A further consideration is that the selection of a particular program or service must be based on the person's needs and wishes—not just on the options currently available in the service system.

There is a relatively simple test for dealing with the issue of determining least restrictive alternative. In trying to decide whether a specific living situation fits the criterion of least restrictive alternative, one must ask whether there are examples of persons with similar needs being appropriately served in other, less restrictive, settings. This type of test was critical to the landmark Pennhurst Case (Laski, 1980). The basic strategy of the plaintiffs was to show that, for each resident living in Pennhurst (a restrictive setting), there was a person with similar needs who was being appropriately served in a less restrictive setting. After being presented with many such examples, the judge concluded that an institutional environment was not necessary to meet the resident's

needs—in that each Pennhurst resident had a "functional twin" living in an appropriate, less restrictive, community-based setting.

It is important to point out that application of the principle of least restrictive alternative does not mean that Ohio will be able to provide all persons with age and culturally appropriate, typical residential settings. However, application of this principle does require that placement of a person in settings other than these be proven as necessary to meeting the person's needs. In other words, the basic planning assumption should be that all individuals will live in small, well-integrated, positively valued settings. Any deviation from this strategy, toward more restrictive settings, can only be undertaken after proof that the person's needs cannot be met in less restrictive alternatives.

RIGHT TO SERVICES

The assumption of a right to services concerns the right of a person to services or treatment that promote growth toward increased independence and competence.

While a person may benefit from congregated and segregated programs, it is questionable whether such programs provide an adequate treatment or service environment. Given that the ultimate goal for all persons is for them to live as much as possible in a complex, heterogeneous, community-based setting, the adequacy of any institutional setting must be questioned. How does the congregation of large numbers of persons with developmental disabilities in physically and socially segregated settings contribute positively towards enhanced independence, competence, or social awareness?

NORMALIZATION PRINCIPLE

Normalization refers to ". . . the utilization of as culturally valued means as possible in order to establish and/or maintain personal behaviors, experiences and characteristics that are as culturally normative or valued as possible" (Wolfensberger, 1980). This principle calls attention to (1) what the residential program achieves for those to whom it provides services (the "goals") and (2) how the program achieves these objectives (the "means" in the definition).

Appropriate application of the normalization principle results in the development of residential services that ensure as much as possible the person's presence and participation in typical community life.

EQUAL JUSTICE

Adherence to the concept of equal justice requires that persons with developmental disabilities be provided services and supports that will allow equal opportunity for growth and development. Each person with developmental disabilities, as do other members of society, has a right to receive services from publicly supported programs. The arguments used with respect to Right to Services are relevant here also. In a variety of places across the United States, persons with severe handicaps are being served in quality, integrated community settings (Apolloni, Cappuccilli, & Cooke, 1980; PCMR, 1978). The principle of equal justice requires that Ohio's long-range plans be based on the assumption that all persons can participate in community life. So long as persons with developmental disabilities are forced to live in restrictive segregated settings, only because appropriate community alternatives have not been developed, the concept of equal justice will not have been applied appropriately.

RESPECT FOR HUMAN DIGNITY

While a respect for human dignity may seem to be more abstract than the other planning principles, it is still extremely important. Human dignity is closely related to a person's ability to make choices, select and maintain possessions, to be treated with respect, to live in surroundings that foster individuality and allow for privacy, to participate in the development of his or her own service plan, and to receive services and supports tailored to his or her unique needs. Most persons have characteristics and competencies valued by others. They can usually advocate for themselves and can, therefore, gain at least a minimum of dignity and respect.

Except in very limited ways, persons with severe handicaps cannot gain the same degree of dignity and respect by their own actions. It is, therefore, extremely important that they be treated with respect and served in settings that are as positively valued as possible.

DEVELOPMENTAL ASSUMPTION

Traditionally, mental retardation and other forms of developmental disabilities have been looked upon as "health problems," and services have been structured on a medical model. Many needs, such as communication, personal skills, homemaking, and social skills, were attributed to the person's developmental disability and viewed as being a sickness or physical problem, remediated or met by medical settings and approaches, medical processes, and medicines.

Planning Principles

Persons with disabilities were perceived as having limited potential. In part, institutional services have been based on the medical model.

However, since knowledge of developmental disabilities has expanded, it has become clear that a developmental disability is not primarily a health problem. A disability is not the same as an illness nor, very often is there a cure. Developmental disabilities are conditions, stemming from physiological or psychological handicaps that significantly curb or affect a person's development. If developmental disabilities are a developmental problem, then they must be approached as such. Human beings, by their nature, grow, change, and develop; persons with developmental disabilities are not exceptions. The only difference is that persons with developmental disabilities need specialized, sometimes long-term, help to develop as fully as possible.

The developmental assumption is considered by most authorities to be a desirable approach to serving persons with developmental disabilities and serves as a basis for valid service development and delivery. The developmental assumption is based on two principles:

- Life as Change: Human beings are in a constant state of change from the time of conception until death. (The assumption that persons with developmental disabilities are often physicially and psychologically fixed or unchanging is, in effect, to deny their humanity; all persons, regardless of the type or degree of handicap, have the potential for positive growth.)

- Modifiable Development: The rate of development is influenced by interactions of many internal and external factors, including inherited characteristics, health, and the external environmental setting. (The rate, direction, and ultimate level of development can be influenced through teaching, and by utilizing and controlling certain physical, psychological, and social aspects of the environment.)

A primary goal of programs for persons with special needs should be to increase the adaptive behavior and general competencies of the individual by modifying the rate and direction of behavioral change. Persons with developmental disabilities should be approached from the standpoint of being capable of growth, learning, and development. They should be considered in a state of constant change that can be significantly influenced by conditions imposed within the environmental setting. Persons with developmental disabilities have normal developmental stages of infancy, childhood, adolescence, and adulthood. Within each stage, different needs are

emphasized. Although these stages may be delayed in varying degrees, persons with special developmental needs should not be subjected to socially imposed perceptions that limit growth.

The primary implication of the developmental assumption is that programs be oriented toward the individual, and that program goals be dynamic and individually defined. Residential programs should be designed to be as growth-enhancing and supportive of learning as possible. Institutional settings, which tend to congregate large numbers of persons with special needs and segregate them from normal community activities, are not consistent with the developmental assumption.

EFFECTIVENESS AND ECONOMY

It is paradoxical that one of the most frequently cited reasons for large congregated settings, that they provide effective service and treatment, is not supported by research findings (McCarver & Craig, 1974; Pilewski & Heal, 1980). Recent research shows that it is very important, especially for persons with severe and profound handicaps, to participate in training programs that are as similar as possible to normal community settings (Martin, Rusch & Heal, 1982). This is especially important for persons with mental retardation because of their difficulty in generalizing from the original learning environment to other settings.

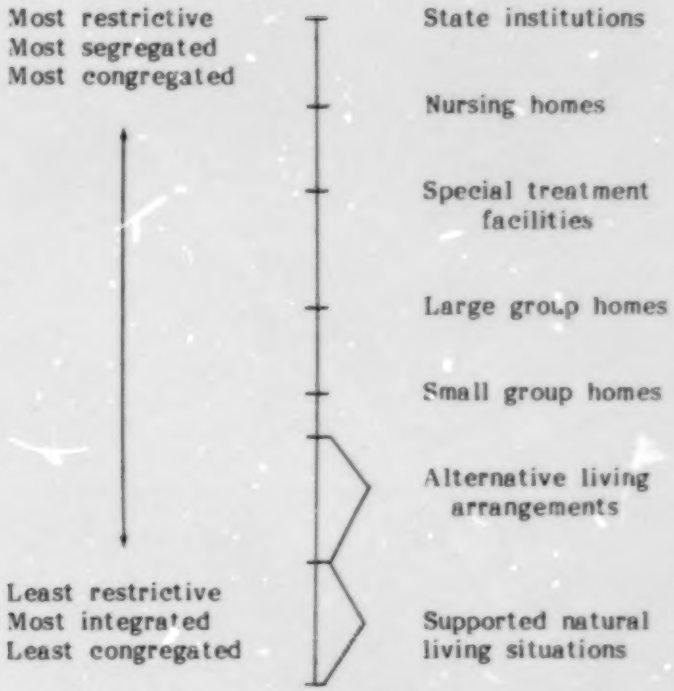
It is ironic that the other reason for the development of large congregated settings, economy of service delivery, is not supported by cost data. A number of studies have shown that quality, community-based programs can be provided at no more, and in some cases less, cost than institutional care (Boggs, 1981; Lakin, et.al., 1982; Touche-Ross, 1980). A number of states, including Pennsylvania, Texas, and Vermont, have limited or are in the process of limiting the size of community residential programs for persons with developmental disabilities (Toff, 1982).

However, there is an important complication to the economic analysis. Cost incentives and disincentives must be analyzed separately for each of the major "actors" in the deinstitutionalization movement. It is important to ask "cost savings to whom?" (the federal government, state or local government, the family, etc.)

Although cost considerations are important, it is more important not to lose sight of humanitarian considerations in providing community-based residential programs.

CRITICAL ANALYSIS OF CURRENT PLANS

Most states have long-range plans that call for a continuum of residential services. The assumption is that different programs (usually based on different environments or settings) are necessary to meet the full range of service needs. An example of one such residential continuum follows:



DESCRIPTION

The continuum approach is based on the assumption that persons with the most severe disabilities are appropriately placed in more restrictive settings (nursing homes, special treatment facilities) and persons with less severe disabilities in less restrictive settings, with the rest of the persons "placed appropriately" across the continuum. The hope is that if the continuum is comprehensive, there will be no service "gaps"—all persons will be placed in an appropriate program. A brief description follows of the types of programs commonly found in states using the continuum strategy.

- o Institution: Large, state-operated residential facility, which provides a variety of services on a 24 hour-a-day basis; traditionally located away from the general population.

- o Nursing Home: A large community facility that provides health related or rehabilitative care and services to the

elderly or chronically ill (skilled care facility, intermediate care facility).

- o Large Group Home: A residential setting that provides room and board, personal care, habilitation services, and supervision in a home-type setting (typically serves 8 to 15 persons).

- o Small Group Home: A residential setting that provides room and board, personal care, habilitation services, and supervision in a home-type setting for not more than 8 persons.

- o Alternative Living Arrangements: A range of residential options from semi-independent living (no live-in staff but with daily supervision and training) to residential settings for a small number of adults (fewer than 6), with full-time staff supervision and support--apartments, homes, etc..

- o Supported Natural Living Situations: Living situation that is typical for a person's age or community (independent living with periodic support provided; person living with his or her family).

NEGATIVE ASPECTS

The development of such a comprehensive continuum does indeed offer advantages over the historical approach of offering only institutional services. However, there are a number of problems with the continuum approach.

Resources Go to Restrictive Settings

Most of the resources go to the more segregated, more restrictive residential settings. Development usually begins with institutional reform, then moves to development of special care facilities and large group homes. Very few resources then are left to support more integrated alternative living arrangements and supported natural living settings.

Movement Based on Improvement

Movement from more to less restrictive settings is presumed to be a function of improvements in the person's behavior or condition. There are many problems with this approach.

- o Forced to Earn Rights: Persons with disabilities are forced to "earn" their right to live in less restrictive, more positively valued settings. Many persons, especially those with severe disabilities, will never "earn" this right.

Critical Analysis

- o Individual is "Type Cast": The entrance and exit criteria approach of the continuum strategy presumes that persons can be "type cast" as group-home client, foster-home child. If the person changes, he or she can move on through the continuum. This strategy reinforces the notion that certain persons can be served only in specific settings; service programs are not seen as having any flexibility in providing for the person's support.

- o Little Movement: Studies have shown that there is not much movement through the residential continuum. One study shows that approximately one-half of community residential programs reported no movement in or out of their program in the previous year (Bruininks, Hauber, & Kudla, 1979).

- o Depends on Availability of Options: The continuum strategy presumes that persons move or "graduate" through the system as they gain in competencies and decrease in maladaptive behaviors. While of course this is sometimes true, it is clear that most moves through the system occur because of the development of more integrative service options. This is an especially important issue for persons with severe disabilities. Most persons with severe disabilities will not earn their way to more typical, positively valued settings. However, a number of programs have shown that even persons with the most severe disabilities can live in small, community-based settings if the service system is willing and able to provide the necessary supports.

Reinforces "Differences"

The continuum approach reinforces and deepens the perception of difference between persons with disabilities and other, nondisabled citizens. Much of our public education effort focuses on reducing this devaluing perception, yet the success of such educational efforts is diminished through the development of a continuum that ensures that nondisabled persons will not live near, nor go to school or work with, persons with disabilities.

Cost

The cost of fully implementing the continuum is enormous. Most of the living environments on the continuum are "special" facilities, which usually involve major renovation or new construction.

No Individualized Program

It is not possible to provide a truly appropriate residential program in congregated, segregated settings. All of the specialized services and supports usually associated

with segregated programs can be provided in more integrated settings. However, it is not possible to provide really individualized programs, with exposure to normal or typical role models, in segregated, congregated settings.

Also, persons with severe disabilities often have great difficulty learning new skills and even greater difficulty in generalizing these skills to new situations. Research findings support a strategy of providing training in settings that most closely resemble the final living situation (Martin, Rusch, & Heal, 1982).

HOME-CENTERED APPROACH

Persons with disabilities, both children and adults, should be supported in the most natural, most valued setting possible. The transition from facility-based (least valued) to community based (most valued) residential settings is shown in figure 1. Families should be supported (both financially and through support services) to help them keep their children with disabilities at home while growing up. Even with appropriate supports, some families will not be able, or want, to keep their children—adoptive and foster homes could then provide alternative living arrangements.

Also, adults should live in their "own" homes. Whether they actually own the building in which they live, is not as important as the understanding that it is their home—not simply a facility in which they live.

It should be noted that the support of "home" and natural settings is not incompatible with providing special equipment, paid staff, or other highly specialized services.

DESCRIPTION

The continuum approach is based on the presumption that specific types and levels of care and supervision can only be provided in special, usually segregated, settings. The home-centered approach is based on the view that natural environments are elastic and can be accommodating of differences, and services are flexible and supportive (Galloway & Chandler, 1978).

Figure 1

Transition in Residential Services for Persons with Developmental Disabilities

10

SEGREGATED,
CONGREGATED,
RESTRICTIVE,
FACILITY-BASED

INSTITUTION:

COTTAGES ON
INSTITUTIONAL
GROUNDS:

COMMUNITY
INSTITUTIONS:

PHYSICAL &
SOCIALLY INTEGRATED,
LEAST RESTRICTIVE,
HOME-CENTERED

SMALL HOME-CENTERED
RESIDENTIAL
OPTIONS:

19

20

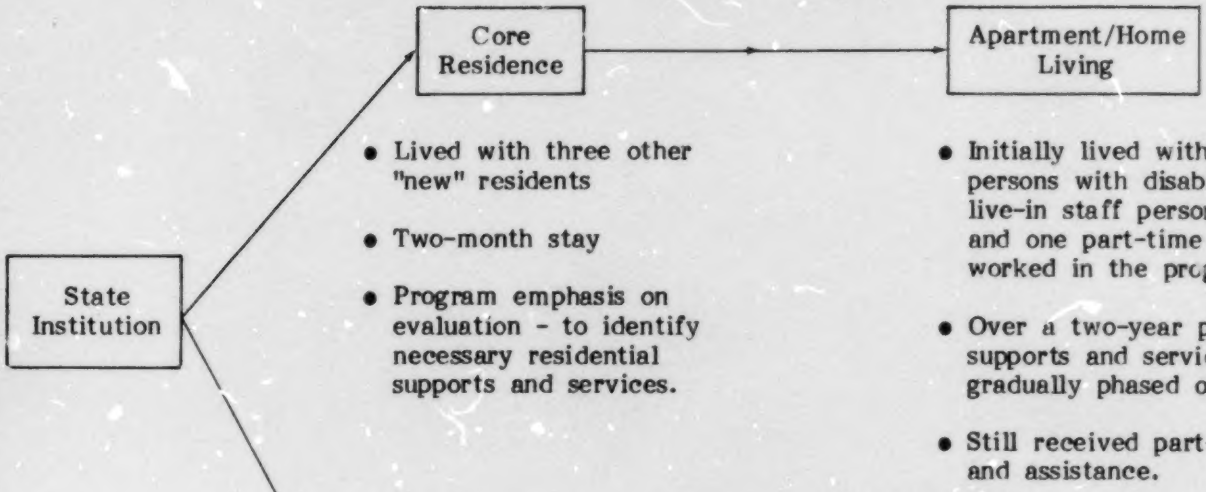
Instead of employing the step-by-step "movement toward normalization" approach of the continuum, the home-centered approach calls for moving the person to a situation similiar, if not identical, to the "final" target setting. The provision of special, artificial supports and services is often required to accomplish this. However, for those persons who later show gains in competence, such supports can slowly be removed. This type of approach allows for the development of much more individualized, more realistic training and living situations.

MAJOR DIFFERENCES

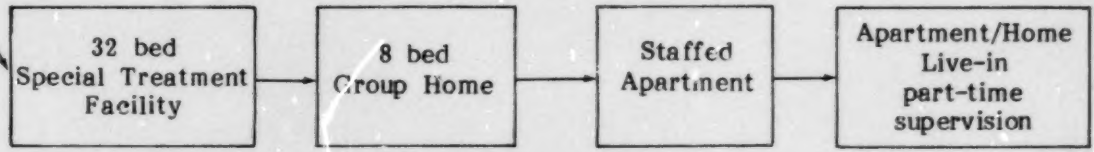
A major difference between the home-centered and the traditional continuum approaches is shown in figure 2. Note that in the continuum approach, a person may be required to make four residential moves over a period of several years. The person would have to learn new relationships with approximately 25 to 40 staff and about 25 to 30 other persons. These changes could lead to considerable frustration and require additional "training" programs in each setting because previously taught skills did not generalize to the new living situation. Only in the final living situation can the person begin to develop a feeling of home and permanence. In contrast, a home-centered approach requires that the person make only two moves. New relationships would need to be learned with no more than 10 staff and 5 other persons. Within a short period of time, the person would be in a home setting. Teaching programs to increase both appropriate behaviors and competencies could then be provided in a typical, realistic living situation. Program costs could be reduced by gradually phasing out services, not by requiring the person to move to a new, less restrictive setting.

Other differences between the home-centered and the traditional continuum approaches involve the attitudes, philosophies, and expectations reflected in each approach. In particular, there are potential differences in how each approach reflects terminology, community presence and participation, program functions, and the types of decision-making encouraged. Some of these potential differences are shown in figure 3.

Figure 2
HOME-CENTERED APPROACH


State Institution
Core Residence
Apartment/Home Living
• Lived with three other "new" residents
• Two-month stay
• Program emphasis on evaluation - to identify necessary residential supports and services.
• Initially lived with two other persons with disabilities and a live-in staff person (one full-time and one part-time person also worked in the program).
• Over a two-year period special supports and services were gradually phased out.
• Still received part-time supervision and assistance.

CONTINUUM APPROACH



- Initially placed in a special treatment facility because he did not meet the entrance requirements of the group home.
- After meeting criterion on self-care skills, was moved on.
- Program focus in group home was on decreasing problem behaviors.
- Moved to apartment with live-in staff; focus on community living skills.
- Finally moved to a new apartment; still needed part-time assistance.

Figure 3

POTENTIAL DIFFERENCES BETWEEN A FACILITY-BASED AND HOME-CENTERED APPROACH TO RESIDENTIAL SERVICES

Facility-Based	Home-Centered
Language	
Clients, residents, patients	Persons with disabilities
My clients, our residents, our population	The persons who live here
Group home, residential facility	House, home, apartment
Ravenwood, Brown Home #1, Guiding Light Center	2165 Upper Arlington Road
We program the clients three-four hours per day	We assist them in learning new skills
We have a vacancy (an empty bed)	There is room for another person in our home
Community Presence and Participation	
Six to sixteen residents per facility	One to five persons in any one living situation
Large facilities located mainly in fringe and transitional neighborhood, to minimize community opposition	Small homes, apartments located in positively valued neighborhoods
Transportation provided almost totally by "special" means, such as facility-owned vehicles, county program buses	Maximum use when possible of generic transportation services
Emphasis on large group activities; in typical situation everyone goes shopping, bowling, at the same time	Emphasis on individual and small group activities with non-settings
After program opens, little effort is made to interact with neighbors and to portray clients as members of neighborhood	Staff systematically assist persons with disabilities in active community participation
Program Function	
A community-based facility designed to house a population of disabled clients	A place to live in the community, with appropriate supports and services
Clients receive a wide range of habilitative services; at the extreme the facility provides for all of the client's 24 hour program needs	Persons with disabilities are assisted in acquiring functional competencies related to their living situation (would not serve both day and residential program needs)
Emphasis on cleanliness, health concerns, client supervision, training and protection	Program guidelines attempt to balance need for supervision and protection with the person's rights regarding "Dignity of Risk"
Many children live in the facility; served by staff who work on shifts	If supports of the natural family are not possible, children live in alternative family situations
Decision Making	
Residents follow pre-existing facility rules developed solely by management	Everyone living in the home plays a role, if possible, in developing and modifying the rules for home living
No authority conflicts, resident must follow the rules	Potential for authority conflict (residential provider has contract obligations for services and supervision, which may conflict with resident's right to make decisions)
Staff allowed to violate many rules that apply to clients	House rules apply to everyone who lives or works there.

ISSUES SPECIFIC TO CHILDREN

The best place for children to grow up is in a family setting--preferably with their natural family. Functional support for this position involves the development of a full range of family supports--through a variety of in-home supports and services (Hitzing, 1982).

For those children whose families cannot or will not keep them, adoption or foster home placement can still provide a family-oriented living situation. However, major commitment to the development of a comprehensive foster care program requires a radical departure from traditional approaches to foster home placement. The few high quality foster placement programs that have been developed are characterized by:

- o A relatively high level of financial supports to the foster family
- o Extensive back-up supports and services such as in-home training, crisis assistance, and respite services
- o Consistent program monitoring, evaluation, and management

It is clear that while the transition from a facility-based to home-centered system is in progress, parts of our present facility-based residential service system will need continued support. However, these programs will no longer be considered as necessary to meet the child's needs. They are now, and will continue to be, necessary because we have not developed and adequately supported natural and foster family settings.

Accepting a home-centered approach to residential services for children will not require the immediate elimination of all congregate, non-family, living situations. However, we can accept a home-centered approach as providing a positive, long-term goal to guide decisions regarding resource allocation and service development.

ISSUES SPECIFIC TO ADULTS

The application of a home-centered approach to the development of residential services for adults is a radical departure from our current, largely facility-based approach. Applying the home-centered approach to services for adults is more complex than applying it to services to children. No one living arrangement can be viewed as meeting the needs of all adults, as the family-based model does for children. A variety of options will be necessary. For example:

- o Independent living with periodic technical assistance by a case manager or other support staff
- o Semi-independent living with no live-in staff, but with daily supervision and training
- o Alternative living arrangements, with small numbers of adults, and full-time staff supervision and support

A home-centered approach is inconsistent with any significant congregation or segregation of persons with disabilities. Twelve-bed cottages are often described, especially in program brochures, as home-like. Yet, after visiting them, no one would mistake them for a typical home.

Attitude and Philosophy

A home-centered approach has an equally profound effect on the service attitude or philosophy of the residential program. The current facility-based approach fosters an "our client," "treatment-oriented," "us serving them," service mentality. A home-centered approach emphasizes the role of the residential program in assisting and supporting adults to live as independently as possible in the community. Ohio will need to place more resources into supports for independent and semi-independent living. For those persons requiring more care and supervision, small, well-integrated alternative living arrangements should be developed. However, even in these small group settings the adults should be seen more as citizens who need special supports and services and less as "clients" involved in residential treatment programs.

Independence Versus Interdependence

It is important to note that promoting the person's right to independence (personal control over decisions relating to his or her life) is not inconsistent with the concept of interdependence. Most persons with severe disabilities will always depend, to some degree, on support from a service system. Independence, if translated to mean isolated placement in the community without supports and without social ties, is not a legitimate goal. The purpose is to help persons with disabilities to increase the quality of their lives, not simply to meet the requirements of some abstract philosophical principle.

ISSUES SPECIFIC TO PERSONS WITH SPECIAL NEEDS

A home-centered strategy can also be used in serving persons with special needs, such as those with severe behavior problems, chronic medical problems, deafness/blindness, or older persons with developmental disabilities. This does not mean that the necessary training and supervisory aspects of

a residential program can be neglected; only that one can break with the historical mind-set that special needs can only be met in very special (usually large and segregated) settings.

Small Size Not a Limitation

A number of programs across the country have shown that small size is not a limitation, but usually an asset. In fact, small programs have successfully developed the types of intensive and individualized programs necessary for persons with severe behavior problems. The Jay Nolan program in California, and Project TEACCH in North Carolina, are examples of small, successful programs that meet the needs of persons with severe behavior problems. In addition, the Developmental Maximization Unit of the Eastern Nebraska Community Office for Retardation (ENCOR) has a long record of successfully serving profoundly handicapped children who have chronic medical problems, in a small community-based setting.

Because of the relatively small number of people needing such specialized services, these programs often serve a multi-county or regional catchment area. However, this multi-county orientation is not incompatible with a small, well-integrated service strategy.

It is difficult to apply the philosophy or basic attitude of a home-centered approach to persons with very special needs. It may be difficult for most people to think of four adults with profound handicaps and severe behavior problems as living in "their own home" and being supported by an intensive program of supervision and care. However, as was pointed out previously in the section on Planning Principles, the human dignity and status of persons with severe disabilities probably depends more on where they live and how they are treated than on their own actions and competencies. A home-centered approach to serving persons with special needs should increase their status as valued community members.

Elderly

Another "special needs" group deserves specific attention—older persons with developmental disabilities. In the name of normalization, some people have rationalized the placement of older disabled citizens into nursing homes. Nursing homes are considered a typical or "normal" response to meeting the residential needs of older, nondisabled citizens. This type of statistical approach to the principle of normalization is a trap that needs to be avoided. A number of progressive service programs for older citizens, such as the Minneapolis Aging and Opportunity Center, have developed a wide array of support programs to assist persons in staying in the community and out of institutional settings. Such programs are much more cost efficient and more consistent

with the basic planning principles described earlier. These programs should serve as models of future program development.

MANAGEMENT MODEL NEEDED

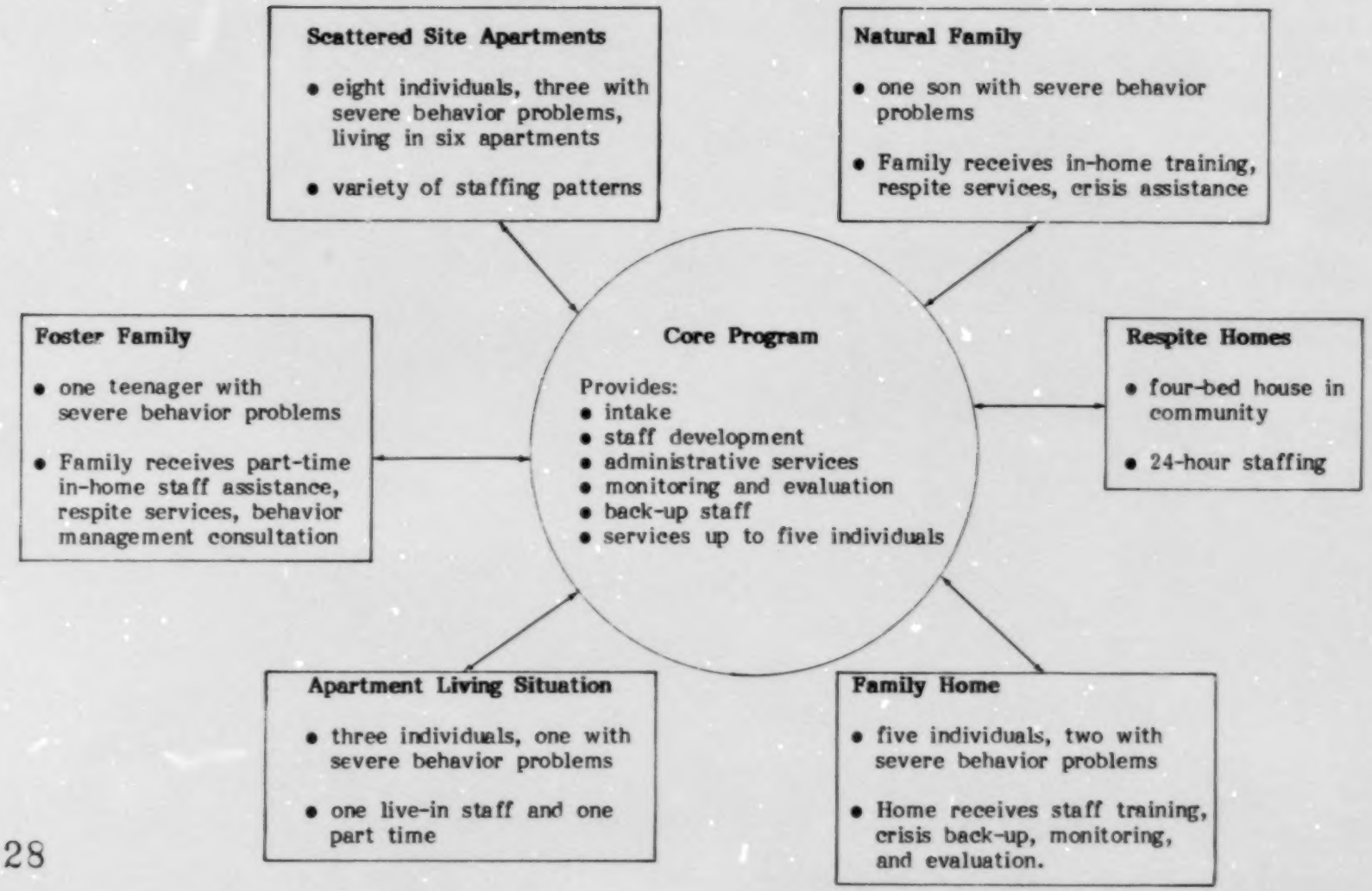
The development of integrated residential options will require more efficient and effective management models at the local level to coordinate and support the various residential settings that will be necessary to meet the needs of persons with developmental disabilities. Figure 4 shows the core-cluster management model used by ENCOR to successfully serve persons with development disabilities in dispersed, integrated settings. Persons with developmental disabilities enter the system by first living in the CORE program, and then quickly move to one of a variety of alternative living arrangements (the cluster). The program attempts to serve as few persons with disabilities as possible in any one living situation. The Core residential program provides the necessary assistance, training, and support services (Skarnulis, 1976).

A variety of other management models could also be successful. Whichever model is chosen, it is clear that it must provide:

- o Comprehensive individual evaluation in realistic, normalized settings so that appropriate, alternative living arrangements can be selected or developed
- o An adequate resource base to fund appropriate staff, special supports and services
- o Flexibility in individual placement and evaluation
- o Ongoing staff development
- o Consumer involvement in all aspects of program planning, implementation, and evaluation

Figure 4

CORE-CLUSTER SERVICES STRATEGY


Scattered Site Apartments
• eight individuals, three with severe behavior problems, living in six apartments
• variety of staffing patterns
Natural Family
• one son with severe behavior problems
• Family receives in-home training, respite services, crisis assistance
Foster Family
• one teenager with severe behavior problems
• Family receives part-time in-home staff assistance, respite services, behavior management consultation
Core Program
Provides:
• intake
• staff development
• administrative services
• monitoring and evaluation
• back-up staff
• services up to five individuals
Respite Homes
• four-bed house in community
• 24-hour staffing
Apartment Living Situation
• three individuals, one with severe behavior problems
• one live-in staff and one part time
Family Home
• five individuals, two with severe behavior problems
• Home receives staff training, crisis back-up, monitoring, and evaluation.

TRANSITION

Due to the interdependence of Ohio's service programs, the development of a "home-centered" residential system for persons with developmental disabilities will require a variety of changes in other aspects of Ohio's service system. For example, the school age and preschool programs—both County Board of MR/DD and public school operated—will need to be more effective and realistic in preparing individuals to live in the community. Skill training in daily living must begin early to ensure that each person will have the necessary skills to function most effectively and independently in a home-centered environment.

Vocational and adult day program services will need to be developed to complement each person's living environment. The overall impact of a home-centered approach will be greatly increased if realistic, work-oriented day programs are provided. It does not make sense to attempt implementation of a residential program that focuses on the development of age and culturally appropriate roles and activities, yet have the persons served in a day program that provides only "make work," devalued activities.

In addition, an emphasis must be placed on ensuring that a variety of generic resources are available and coordinated through an effective case coordination system. Service delivery at the local level must be integrated to ensure that the total needs of each person can be met in a cohesive manner, and that different community-based programs are not working at cross-purposes.

CONCERTED EFFORT

The transition will necessitate a concerted effort to obtain family, professional, and community acceptance of the "home-centered" concept. Without support from a variety of groups, implementation of such an approach is not likely to succeed. In part, successful implementation will depend upon the cooperative efforts of various service organizations, professionals, community leaders, consumer groups, and the general public. Public information and education programs, meaningful mechanisms to facilitate public discussion and input, and comprehensive pre- and in-service training programs will be needed.

LONG- AND SHORT-TERM PLANS

The transition to a home-centered system will be a lengthy process; such a system of residential services cannot immediately be implemented. But, if it is to be developed, planning must begin now. In this paper, the Deinstitutionalization Task Force recommends a direction that

the state may take in developing its residential system for persons with developmental disabilities. If this direction is to be taken, both long- and short-term plans must be developed.

COMMUNITY INSTITUTIONS

Presently, the state is under a great deal of pressure to reduce the population of developmental centers. However, this short-term need cannot be viewed separately from long-term goals. Since large community institutions are not consistent with a long-term, home-centered plan, it would be a serious mistake to continue the transinstitutionalization of persons from state institutions to community-based institutions. Tremendous sums of money would be necessary to establish a sufficient number of community institutional facilities—funds which would have to be diverted from the development of smaller, more integrated living alternatives. Every effort should be made to restrict the development of new community institutions. In addition, local communities should begin to plan for the eventual phase out of existing large community institutions. The state will need to re-examine its present plans to ensure that short-term plans contribute, as much as possible, to the attainment of long-term goals. Although some compromises may be needed, it is imperative to remember that long-range planning does not deal with future decisions, but with the future of present decisions.

RESIDENTIAL RECOMMENDATIONS

GENERAL

- **Independent and semi-independent living options should be developed for persons with developmental disabilities.**
- **Home-centered, residential options should be available in the community for persons with special needs, such as those with multiple handicaps, severe behavior problems, or chronic medical problems.**
- **Home ownership programs should be developed to allow qualified persons with developmental disabilities to purchase their own homes.**
- **A comprehensive, adequately funded, family support system should be developed.**
- **Support services should be developed in the community to assist residential programs in meeting the needs of individuals with developmental disabilities; support services should include those needed to meet the needs**

of persons with severe handicapping conditions and behavior problems.

- Short-term, crisis intervention services should be available for individuals experiencing adjustment problems, and the responsibilities of the various agencies involved in crisis situations should be clearly delineated.

- Individual habilitation plans should be jointly developed by the various agencies providing services to persons with developmental disabilities.

- An ongoing process should be created for identifying individuals who previously were inappropriately placed, and plans developed to ensure their movement to more appropriate settings.

- Appropriate criteria for placing an individual from a developmental center into a community residential program should include:

  (1) Basing placements upon the individual's needs

  (2) Providing a better environment for the individual than the present living arrangement

  (3) Placing the individual in settings with adequate and available community resources and support programs

  (4) Placing the individual in small, community residential programs

  (5) Ensuring that the individual or parent/guardian has had an opportunity to participate and is supported in the placement decision

- Workable agreements for providing community services should exist with generic service agencies such as county children's services boards, mental health agencies, etc.

PLANNING

- A state plan should be drafted for the development of a home-centered residential service system in Ohio.

- Residential planning should be an integral component of a community's comprehensive plan for services to persons with developmental disabilities.

- Community involvement in residential planning and development should be broad-based, and especially include families and consumers.

Recommendations

TRAINING AND TECHNICAL ASSISTANCE

- o Staff development program(s) should be developed to ensure the availability of trained residential personnel, especially at the paraprofessional level.
- o Training options for Qualified Mental Retardation Professional (QMRP) certification of residential personnel should be expanded.
- o Technical assistance and consultation should be made available to assist residential providers in planning, developing, and operating residential programs for persons with developmental disabilities.
- o Ongoing training should be provided to ensure uniform interpretation of rules and regulations governing residential programs.

FUNDING

- o Funding for residential services should reflect present, not historic, costs.
- o A financial subsidy program should be developed to reimburse families for the special costs of raising their disabled son or daughter that cannot be paid for through existing sources.
- o The feasibility should be explored of establishing a statewide housing authority to assist local communities in identifying, developing, and securing capital funds (public and private) for residential development; its mission should include housing for persons with special needs.
- o Funding for new residential programs should be restricted to residential programs serving eight or fewer individuals, and should be used to encourage the development of even smaller programs.
- o Barriers and disincentives relative to the utilization of Title XIX (ICF/MR) funding for small, home-centered programs should be eliminated.
- o Funding for residential services should be allocated equitably to support individuals presently leaving state institutions, as well as those individuals currently residing in the community and in need of residential services.

- Funding for residential services should be based on the individual's needs and services rendered, not on the type or size of the facility.

MONITORING AND LICENSURE

- Minimum standards and criteria that address quality of life and normalization principles should be included in licensure rules and in the monitoring/evaluation processes for residential programs.

- Consumers and consumer organizations should be encouraged and assisted in monitoring the quality of service in residential programs.

- Residential providers should be assisted and encouraged to develop internal evaluation procedures that identify the strengths and weaknesses of their administrative process and of the individual's program.

- An appropriate and efficient external monitoring system should be established that includes measures to assist residential providers in correcting identified weaknesses.

- Licensure rules should permit and encourage the development of small residential programs, semi-independent and independent living options.

- Minimum qualifications for residential operators should be established, and their responsibilities should be clearly delineated.

- Rules and regulations governing residential programs should permit flexibility regarding the level of supervision and programming that is appropriate to meeting an individual's needs. (Currently, regulations "force" more structure and services than are needed for some persons, while other persons with severe needs cannot be served.)

- The various responsibilities and procedures for licensure should be consolidated and clarified.

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